



Issues to Consider When a Child With a Disability Turns 18

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Decision Making

Upon turning 18, your child is legally an adult

There are several different approaches to helping with decision making

Care must be given to the needs and abilities of the person with a disability as well as the family's ability to give that support.



Advance Directives

- LEAST RESTRICTIVE
- Appoint a healthcare representative. You should appoint someone you trust who will:
 - act on your behalf if you aren't capable
 - Be authorized to speak with your physician
- Define the types of medical interventions and life support measures you want.



Power of Attorney

Authorize someone to handle your legal and financial matters.



Supported Decision Making

- A comprehensive plan for decision making codified in 11 states
- Individual creates a written agreement identifying resources in various areas.
- The individual's wishes are paramount. The supporter is in the role of advisor.
- www.supporteddecisionmaking.org

Conservatorship Process

- MOST RESTRICTIVE
- A conservator is a person appointed by the probate court to oversee the financial and/or personal affairs of an adult whom the probate court has judged incapable of managing his or her self-care or affairs.
- A conservator may be appointed voluntarily or involuntarily, and can be a:
 - conservator of estate (appointed to oversee the conserved person's financial affairs)
 - a conservator of person (appointed to manage his or her health care decisions)
 - or both
- Voluntary vs. Involuntary

Guardianship

- MOST RESTRICTIVE
- Guardianship can be established for an individual over 18, by the probate court located in the individual's town of residence if the individual's IQ
- Two types
 - Guardianship of the Person
 - Guardianship of the Estate



Planning Involves Evaluating ...

- The personal needs of the person with disabilities;
- The private assets of the person with disabilities and/or their parents;
- The needs of other family members;
- Availability of caregivers and support within a family;

Planning Involves Evaluating...(continued)

- Caregivers and support outside of a family;
- Public benefit programs to provide support;
- Public resources to assist the person with disabilities so he or she may live as independently as possible; and
- How to enhance quality of life for a loved one with disabilities.

Types of Public Benefits

- Means tested Public Benefits – SSI and Medicaid, including Medicaid waiver programs – for persons with disabilities but also one must “qualify” financially to receive these supports.
- Entitlement Public Benefits – SSDI (Social Security Disability Insurance) and Medicare – these are not means tested benefits for persons with disabilities.
- Examples of other benefit Programs: Section 8 Housing, housing vouchers, Food Stamps, energy subsidies, and respite care.



Public Benefit : Cash Assistance

- SSI – Supplemental Security Income
 - 2020 max benefit is \$783 per month
- SSDI – Social Security Disability Income
 - When parent retires or becomes disabled, if child is 18+ and disabled prior to age 22, child can receive 50% based on parent's social security record
 - When parent dies, payment increased to 75% of parent's social security record

Types of Public Benefit Programs

Means-Tested Public Benefits

- SSI
- Medicaid

Entitlement Public Benefits

- SSDI
- Medicare

Other Benefit Programs

- Section 8/Housing
- Veteran's Benefits
- Food Stamps

Resource Tests for Medicaid Waivers and SSI

- “Countable resource” limits for SSI:
 - \$2,000 for an eligible individual
 - Measured on the first day of a month
 - Income is an issue- to be discussed
- Connecticut Medicaid asset limit:
 - \$1,600 asset limit for Medicaid waiver programs for eligible individuals
 - Income cap for waivers in 2020: \$2,349 monthly gross.

Issues with SSI Income

- In-kind support and maintenance =
 - Actual receipt of food or shelter (or something that can be used to get food or shelter)
 - Reduces benefit dollar for dollar up to a presumed maximum value (PMV) of 1/3 of the benefit
- Deemed Income =
 - Someone else's income deemed to individual
 - Same household/ duty to support
 - Parents assets deemed to child under age 18
 - Same as to spouses
 - Reduces benefit dollar for dollar after the first \$20

Illustration of Planning with SSI Payment

Parents wish to help their child with disabilities live a better quality of life.... So what can they do?

Parents wish to provide \$800 of additional support to daughter with disabilities so she is able to afford better housing.

Example 1

- If parents give daughter a cash distribution of \$800 per month, the following results:
 - Daughter's SSI is reduced dollar for dollar when she receives a cash distribution in excess of \$20/month.
 - Daughter loses all of her \$783.00 SSI payment for that month.

Example 2: In-Kind Support and Maintenance

- Instead, if her parents pay \$800 towards daughter's rent directly to the landlord then...
- The result is only a reduction of her SSI payment that month.
- Her SSI is reduced dollar for dollar up to a presumed maximum value (PMV) of SSI up to 1/3 (after the first \$20 is available to daughter).
- Beneficiary's SSI check is reduced by \$281 (which is 1/3 of the federal portion of the SSI plus \$20 in 2020).

SSI in-Kind Support and Maintenance

The only 10 “food and shelter” items are:

1. Food
2. Mortgage (including property insurance as required by lender)
3. Real property taxes
4. Heating fuel
5. Gas
6. Electricity
7. Rent
8. Water
9. Sewer
10. Garbage removal

Example 3: Best Result by Using Supplemental Needs Trust

- If parents create an SNT and instead of using the \$800 cash to subsidize rent, they purchase other items (anything other than food and shelter) and daughter's SSI remains in tact.
- Daughter receives a benefit from parents, but her cash assistance isn't reduced or eliminated.

Importance of Using Trusts

- Public benefits can be an integral part of the planning process.
- Supplemental Security Income and Medicaid Waiver Programs have eligibility requirements that may be protected through the proper use of Supplemental Needs Trusts.
- The assets held in proper SNTs will not be counted toward eligibility for most public benefit programs.
- What happens if you do not plan; what's the loss?

In 2020, an 18 Year Old Living to Age 78 Would Miss These Benefits

- The loss of \$783.00 per month of Supplemental Security Income will amount to a lifetime loss of approximately \$850,000.00 (with a \$1.5% cost of living increase annually); and,
- Failing to utilize Medicaid waiver programs may amount to the loss of **Multi-Millions** of dollars over the lifetime of a person with special needs.

Questions?



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Thank You!

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